

GENERAL ASSEMBLY OF NORTH CAROLINA  
SESSION 2025

H.B. 1166  
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HOUSE PRINCIPAL CLERK

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HOUSE BILL DRH40680-MGa-196

Short Title: Reorganize & Fund Rare Disease Adv. Council. (Public)

Sponsors: Representative Carney.

Referred to:

1 A BILL TO BE ENTITLED  
2 AN ACT REVISING THE COMPOSITION AND DUTIES OF THE ADVISORY COUNCIL  
3 ON RARE DISEASES; TRANSFERRING THE COUNCIL TO THE DEPARTMENT OF  
4 HEALTH AND HUMAN SERVICES; AND APPROPRIATING FUNDS TO THE  
5 DEPARTMENT OF HEALTH AND HUMAN SERVICES TO COVER THE OPERATING  
6 EXPENSES OF THE COUNCIL.

7 The General Assembly of North Carolina enacts:

8 SECTION 1. Part 6 of Article 1B of Chapter 130A of the General Statutes reads as  
9 rewritten:

10 "Part 6. Taylor's Law Establishing the Advisory Council on Rare Diseases.

11 "§ 130A-33.65. Advisory Council on Rare Diseases; membership; terms; compensation;  
12 meetings; quorum.

13 (a) Short Title. – This Part shall be known as Taylor's Law Establishing the Advisory  
14 Council on Rare Diseases.

15 (a1) Establishment of Advisory Council. – There is established the Advisory Council on  
16 Rare Diseases within the School of Medicine of the University of North Carolina at Chapel Hill  
17 Department of Health and Human Services to advise the Governor, the Secretary, and the General  
18 Assembly on research, diagnosis, treatment, and education relating to rare diseases. ~~This Part~~  
19 ~~shall be known as Taylor's Law Establishing the Advisory Council on Rare Diseases.~~ For  
20 purposes of this Part, "rare disease" has the same meaning as provided in 21 U.S.C. § 360bb.

21 (b) Advisory Council Membership. – The advisory council shall consist of 19 members  
22 to be appointed as follows:

23 (1) ~~Upon the recommendation of the Dean of the School of Medicine of the~~  
24 ~~University of North Carolina at Chapel Hill, the~~ The Secretary shall appoint  
25 ~~members to the advisory council as follows:~~ the following 15 members:

- 26 a. ~~A physician~~ Two physicians licensed and practicing in this State with  
27 experience researching, diagnosing, or treating rare diseases.  
28 b. ~~A medical researcher with experience conducting research concerning~~  
29 ~~rare diseases.~~  
30 c. ~~A~~ One registered nurse or advanced practice registered nurse licensed  
31 and practicing in the State with experience treating rare diseases.  
32 d. ~~One rare diseases survivor.~~  
33 e. ~~One member who represents a rare diseases foundation.~~  
34 f. ~~One representative~~ researcher from ~~each~~ an academic research  
35 institution in this State that receives any grant funding for rare diseases  
36 research.



- 1 g. ~~One parent of a childhood rare disease survivor.~~  
2 h. One hospital administrator, or the hospital administrator's designee,  
3 representing a hospital in the State that provides care to persons  
4 diagnosed with a rare disease.  
5 i. Two persons age 18 or older who have been diagnosed with a rare  
6 disease.  
7 j. Two persons age 18 or older who are, or were previously, caregivers  
8 to a person diagnosed with a rare disease.  
9 k. One representative of a rare disease patient organization that operates  
10 in the State.  
11 l. One pharmacist licensed and practicing in this State with knowledge  
12 and experience regarding drugs used to treat rare diseases.  
13 m. One representative of the life sciences, biotechnology, or  
14 biopharmaceutical industry that either focuses on research efforts  
15 related to the development of therapeutic products for persons  
16 diagnosed with a rare disease or has demonstratable understanding of  
17 the path to commercialization of such products.  
18 n. Two representatives of a health benefit plan or health insurer, at least  
19 one of whom is a representative of a North Carolina Medicaid  
20 Managed Care health plan.  
21 o. One genetic counselor with experience providing services to persons  
22 diagnosed with a rare disease or caregivers of persons diagnosed with  
23 a rare disease.  
24 (2) ~~The chairs of the Joint Legislative Oversight Committee on Health and Human~~  
25 ~~Services, or the chairs' designees, shall serve on the advisory council. A~~  
26 ~~member of the advisory council who is designated by the chairs of the Joint~~  
27 ~~Legislative Oversight Committee on Health and Human Services may be a~~  
28 ~~member of the General Assembly.~~  
29 (2a) One member appointed by the President Pro Tempore of the Senate.  
30 (2b) One member appointed by the Speaker of the House of Representatives.  
31 (2c) One member appointed by the Governor.  
32 (3) The Secretary, or the Secretary's designee, shall serve as an ex officio,  
33 nonvoting member of the advisory council.  
34 (c) ~~Members Length of Terms. – All initial members appointed pursuant to subsection~~  
35 ~~(b) of this section to the advisory council shall serve for a term of three years, and no member~~  
36 ~~initial member, except for the initial physician members and the initial member representing a~~  
37 ~~rare disease patient organization, shall serve more than three consecutive terms. The initial~~  
38 ~~physician members and the initial member representing a rare disease patient organization may~~  
39 ~~serve for up to four consecutive terms. Thereafter, members appointed by the President Pro~~  
40 ~~Tempore of the Senate, the Speaker of the House of Representatives, and the Governor shall~~  
41 ~~serve for a term of two years; and members appointed by the Secretary shall serve for a term of~~  
42 ~~two, three, or four years, as determined by the chair of the advisory council.~~  
43 (c1) Vacancies and Removals. – Any appointment to fill a vacancy on the advisory council  
44 created by the resignation, dismissal, death, or disability of a member shall be filled by the  
45 appointing authority for the balance of the unexpired term. Each appointing authority may  
46 remove any member appointed by that appointing authority for misfeasance, malfeasance, or  
47 nonfeasance.  
48 (d) Per Diem and Expenses. – Members of the advisory council shall receive per diem  
49 and necessary travel and subsistence expenses in accordance with the provisions of G.S. 138-5  
50 or G.S. 138-6 or travel and subsistence expenses in accordance with the provisions of  
51 G.S. 120-3.1, as applicable.

1 (e) Administrative Support. – All administrative support and other services required by  
2 the advisory council shall be provided by the ~~School of Medicine of the University of North~~  
3 ~~Carolina at Chapel Hill Department.~~

4 (f) ~~Upon the recommendation of the Dean of the School of Medicine of the University~~  
5 ~~of North Carolina at Chapel Hill,~~ Selection of Chair. – The Secretary shall select the chair of the  
6 advisory council from among the members of the council. The chair shall serve in this position  
7 until the expiration of his or her term.

8 (g) ~~The chair shall convene the first meeting of the advisory council no later than October~~  
9 ~~1, 2015.~~ Meetings and Quorum. – A majority of the council members shall constitute a quorum.  
10 A majority vote of a quorum shall be required for any official action of the advisory council.  
11 Following the first meeting, the advisory council shall meet at least quarterly. The advisory  
12 council may meet more frequently upon the call of the chair or upon the request of a majority of  
13 council members.

14 **"§ 130A-33.66. Advisory Council on Rare Diseases; powers and duties; reports.**

15 The advisory council shall have the following powers and duties:

- 16 (1) ~~Advise on coordinating the Governor, the Secretary, and the General~~  
17 ~~Assembly on all of the following:~~  
18 a. Coordination of statewide efforts for the to study of the incidence of  
19 rare diseases within the State and the status of the rare disease  
20 community.  
21 b. Coordination of statewide efforts to increase public awareness and  
22 understanding of rare diseases.  
23 c. Identification of policy issues related to rare diseases and the  
24 advancement of policy initiatives related to rare diseases at the State  
25 and federal levels.  
26 d. The appropriation of State funds to facilitate increased public  
27 awareness of and improved treatment for rare diseases.
- 28 (2) Report to the Secretary, the Governor, ~~and the Joint Legislative Oversight~~  
29 ~~Committee on Health and Human Services Services, and the Fiscal Research~~  
30 ~~Division~~ on behalf of the General Assembly not later than January 1, 2016,  
31 and annually thereafter, on the activities of the advisory council and its  
32 findings and recommendations regarding rare disease research and care in  
33 North Carolina, including any recommendations for statutory changes and  
34 amendments to the structure, organization, and powers or duties of the  
35 advisory council.
- 36 (3) In consultation with accredited medical schools, accredited schools of public  
37 health, and hospitals licensed to operate in the State that provide care to  
38 persons diagnosed with a rare disease, develop resources or recommendations  
39 regarding quality of and access to treatment and services available within the  
40 State for persons diagnosed with a rare disease.
- 41 (4) Advise and consult with the Department, the North Carolina Drug Utilization  
42 Review Board, and the Medicaid Preferred Drug List Review Panel in  
43 developing recommendations, resources, and programs relating to the  
44 diagnosis and treatment of rare diseases.
- 45 (5) Identify additional relevant areas for the advisory council to study and  
46 evaluate."

47 **SECTION 2.** Effective July 1, 2026, there is appropriated from the General Fund to  
48 the Department of Health and Human Services the sum of two hundred fifty thousand dollars  
49 (\$250,000) in recurring funds beginning in the 2026-2027 fiscal year to be allocated to cover the  
50 operating expenses of the Advisory Council on Rare Diseases authorized by Section 1 of this act.

1                   **SECTION 3.** Except as otherwise provided, this act is effective when it becomes  
2 law.